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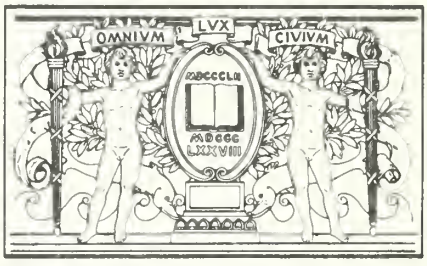


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# Massachusetts Hospice Care in the 80's

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UNITED COMMUNITY PLANNING CORPORATION

# MASSACHUSETTS HOSPICE CARE IN THE 80'S

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SEPTEMBER 1985

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# PREFACE

## HISTORY

In 1981 United Community Planning Corporation (UCPC) conducted a study of hospice care programs serving the United Way of Massachusetts Bay area.[20] This study was subsequently used by UWMB as the foundation of a further study which recommended that some of the start-up costs of some hospices be supported by United Way.

In 1981 there were only 19 fully operational hospices in Massachusetts. In 1984 a Directory was published by the Hospice Federation of Massachusetts listing 47 programs.[7] Some of these operated independently ("freestanding hospices") while others operated as part of visiting nurse associations or hospitals.

During the period 1981-1984 there had been many changes in the field of hospice care. Therefore, the Health Concerns Committee of UCPC decided it was time for a new look at hospice care in Massachusetts.

Research for this report included a search of the literature for descriptions of major trends in the field, interviews with hospice care providers and a survey distributed to Massachusetts hospice care providers.

## CHAPTER ONE

## Introduction to the Hospice Movement in the United States Today

In the previous report prepared by the Health Concerns Committee under the Chairmanship of John H. Clymer in 1981,[20/] the Committee stated that it "strongly advocates the development of hospice services by community-based agencies." The report ended with the statement that information "is currently inadequate and incomplete" to permit an informed opinion as to the future role of the United Way in hospice support. Several options were suggested ranging from delaying any support until a demonstration project had been completed within two years to the "admission of new hospice agencies," presumably for direct financial aid. This report is an update of the previous one and benefits from considerable additional information that has emerged during the past four years. In this interval more hospices have been started, and the entire movement has been subjected to critical scrutiny.

First a definition of hospice according to A. B. Adams:[1/]

> "An integrated program of appropriate hospital and home care for the patient with limited life expectancy. Many definitions include a specific time limit of six months or less. Hospice care is a physician-directed, nurse-coordinated, interdisciplinary team approach to patient care available 24-hours a day, seven days a week. The primary care physician remains a vital member of the team. Psychological and volunteer support are combined with medical management of symptoms. The unit of care, contrary to usual medical practice, is the patient and the family. Emphasis is on home care with inpatient beds serving as a backup for the home care program."

An alternative definition of hospice care was developed for the study issued by United Community Planning Corporation in 1981:

> "Hospice is a concept of care for terminally ill individuals for whom active, curative treatment has ceased and for whom physical, social, emotional and spiritual supportive care has begun. The hospice concept is carried out through a program of care in which an organized, interdisciplinary team provides palliative care -- relief of pain and alleviation of symptoms -- and supportive services to patients. The patient's family, considered a part of the "unit of care," is helped by the interdisciplinary team to take responsibility for the patient's care and to cope with the patient's illness and death. A hospice program's

objective is to create an environment and provide services to make the patient's remaining days as comfortable and meaningful as possible and to help the family cope with the stress of terminal illness and death."20/

No single definition of hospice care captures all the variations in perating philosophies currently seen in this field. However, Appendix wo of this report, which reprints definitions prepared by the National onsumers League, describes in more detail the various components.

In Britain, where hospice programs started about 20 years earlier han the programs in the United States, the approximate distribution of he locations of patients at the time of death from cancer is 59% in hos- itals, 33% at home, and 7% in hospices. In such a program death could ccur in hospice-controlled beds as well as in the other two locations ited.17/

Recent years have seen remarkable developments in the hospice move- ent in the United States that are relevant to understanding the movement nd to making informed decisions as to the merits of supporting the urther development of hospices or of supporting constructive changes ithin the present system. The more important developments are:

1. Federal legislation in August 1982 extended the possibility of benefits to an estimated 266,000 terminally ill Americans annually starting November 1, 1983. This introduced a financial motivation for the expansion of hospice care that seemed desirable to some and appeared to others as a serious threat to the volunteerism and counter-institutional flavor of the early expressions of the hospice movement. This later concern was not relieved by federal regulations that appeared to encourage programs with large case loads in contrast to small, less controlled and more highly individualized free-standing units.

2. The impact on the hospice movement of measures of quality control and cost containment as the entire medical care delivery system was brought under increasingly detailed scrutiny. Objective data were sought and discovered to be largely absent to validate claims of cost savings and improvement in the quality of life for the dying patient and for the bereaved family as benefits of hospice care in contrast to conventional care. Concerns were expressed as to the logical limits of a program which was attempting to enhance the meaning and quality of life for terminal cancer patients when 450,000 Americans die as a consequence of cancer each year.2/

3. The admission requirements for hospices tend to be selective in ways which places them at variance with established practices in Britain. This raises questions as to the necessity of such requirements and their effect on the equity all terminally ill patients might reasonably expect to have in a program financed in large part by community funds or federal taxes.[15] Restrictive requirements such as the applicant giving proof that a primary care person (PCP) is available in the household to assist in personal care of the patient for extended periods or that death within six months is to be expected suggest to some observers that elderly patients living alone or facing a terminal episode not related to cancer were being excluded from appropriate and needed benefits.

4. As a consequence of the perturbations in the evolution of the hospice movement following the above developments in the United States, a new set of interested parties were added to those initially concerned with hospice development. Hospitals, either to gain bed occupancy or to unbundle costly clinical services, developed a stake in hospice development. Health planners saw an opportunity to apply their skills in rationalizing a service that had begun with essentially no central planning. Federal agencies, particularly the Health Care Financing Administration (HCFA) in its financial control of the Medicare and Medicaid programs, saw a responsibility for quality and cost control in their monitoring of health care funds. The committed and enthusiastic band of volunteers that had nurtured the hospice movement in its early years, largely unaided, now were surrounded by unsolicited collaborators with, at times, less than congenial motives.

5. Hospital practice in the care of terminally ill patients has been modified in the past 20 years in large part through experience in modern intensive care units and to a significant extent by the example of hospice care with its commendable accent on quality of life issues. An example of an important modification of hospital practice, apart from the leadership seen in hospice care, is the acceptance of criteria for death based on neurological evidence (irreversible brain death) as equally valid as cardiac evidence (cardiac arrest).[18] This critical development provided the ethical, medical, and legal basis for withdrawing inappropriate medical care at the end of life for many hospitalized patients. Thus the relative indifference observed in some hospitals in the past to the quality of life at its end has been at least partially corrected. A rationale for hospice care has correspondingly decreased.

   Examples of attempts to improve hospital performance are seen in the Kaiser Health Plan of Northern California that operates a modified hospice program within the plan as well as in the North Shore University Hospital's Don Monte Home Oncology Medical Extention (HOME). This is a program that

permits 48% of dying cancer patients to remain at home as compared with the national average of 13%. A study conducted by the Kaiser plan indicated that costs of care were not reduced by their hospice program.[9]

In a thoughtful review of issues and problems confronted in the evaluation of hospice performance, B. M. Mount and J. F. Scott have compared the British with the American system.[15] Six instructive differences illustrate the "drift" of the American plan away from the original British concept. Such a series of changes may well be desirable to some extent because of the unique nature of the medical scene in this country. An awareness of the evolving differences between these two approaches at the present time affords insights into the future of hospices in this country. This could influence recommendations for support. The six differences mentioned by these authors are:

1. The British do not insist that patient and family declare a certain life expectancy. The authors state that "hospice patients are defined not by their anticipated longevity but by the limitation of the current therapeutic armamentarium" in contrast to general American practice.

2. There is more physician involvement in Britain largely as a consequence of the traditions started by Dame Cicely Saunders and Dr. Robert Twycross at St. Christopher's Hospice in South London in the 1950's. They emphasized the complexities of terminal care, need for physician involvement, and demands for perspicacious medical judgments to keep patients comfortable and out of hospitals. In contrast the American scene has more responsibility and authority vested in nurses and social workers partly as a consequence of the relatively limited financial support for hospice care, which tends to discourage physician participation. In a sense the hospice movement in the United States did not establish itself securely before concerns regarding cost containment fostered the false interpretation that hospices were only good if they saved money.

3. There is no such artificial restriction on support for hospice care in Britain as embodied in the existing federal regulations that limit reimbursement for aggregated hospital care for patients in a hospice program to 20% of aggregated hospice care patient-days. The need for hospital care is highly variable. Inflexible limits uniformly applied to programs do not correspond with the clinical realities of terminal care patients and would obviously influence the selection of patients for a hospice.

4. A personal care provider (PCP) is not considered a necessary condition for entry into hospice care in Britain.

5. American practice, not shared by the British, requires that the family and patient are fully informed about the patient's terminal illness and that they give permission for hospice care as an alternative to hospital care. In the process they are exposed to unvarnished facts about the futility of further treatment and brief life expectancy. The British model appears to steer around rather than directly through these disquieting disclosures; but of course, their malpractice environment is not as bizarre as the system in this country where the absence of informed consent for any treatment may be an argument that could surface in subsequent litigation over the indications and adequacies of hospice care.

6. In many hospice programs patient care services are contracted for by the hospice administration in contrast to British (and Canadian) practices where the hospice services are provided by the staff of the hospice. Current federal legislation is designed via reimbursement incentives to motivate hospice programs to become more inclusive like the British model, a regulatory thrust not warmly welcomed by many in the hospice movement in this country.

By merging the facts from two reports[16/,22/] we learn that the National Hospice Organization reported that in 1984 1,000 programs are in operation in the United States providing hospice service to approximately 64,000 patients of whom 95% have cancer.

The first United States hospice was opened in Connecticut ten years ago giving some measure of the rapid extension of this form of care. The Joint Commission on Accreditation of Hospitals in 1981 determined in a survey of 440 hospices that 46% were hospital-based; 26%, community-based umbrella organizations; 23%, home health agencies; and 4%, totally volunteer based. Also in 1981 a survey by the Department of Health and Human Services (DHHS) disclosed that 67% of the hospices required a PCP for a patient to be eligible, a fact to be considered since 29% of the elderly 65 years and older live alone.[21/]

A few studies have been conducted to evaluate hospice care (ten of the better ones are listed by B. M. Mount, et al), but none of these is listed as a randomized controlled study. In 1983 R. Bayer et al, in a review of the care of terminally ill patients concluded that despite many intangible benefits "to what extent the hospice movement will lead to a decrease in the costs of dying is far less clear. Considerably more experience and data will be necessary before any final judgment is reached on the long-term economic benefits of hospice care."[3/]

H. G. Birnbaum et al compared conventional care, hospital-based hospice care, and home-based hospice care for terminal patients in the National Hospice Study (NHS) sponsored by HCFA.[4/] In general the NHS papers reinforce the conventional wisdom that hospice programs based upon a home care program are less costly than those which are "hospital-based." (It should be noted that NHS uses the term "hospital-based" to refer to programs which are affiliated with a hospital or have beds specifically available for hospice care.) It was found that 83% of the patients in hospital-based hospice programs receive some inpatient hospital care while only 43% of home care hospice clients are ever hospitalized. However, the length of stay for these hospitalized home care patients is actually more than twice as long as that for hospital-based patients. The non-random assignment of patients to these two models of hospice care make it impossible to interpret the causes of the modest differences noted in these comparisons.

The NHS analysis of costs focuses on a subsample of 2,900 terminal cancer patients selected from the 25 participating programs.[5/] The report concludes that in comparison to conventional care, home care hospice programs "always seem to lead to savings" and hospital-based programs "can lead to cost increases for patients with long hospice stays (greater than two months)." Since hospice care is less aggressive than conventional care, various expensive types of equipment, medical procedures and tests will not be used. However, this fact does not mean patients selected for hospice care require less medical care management.

The results of the National Hospice Study, insofar as they relate to costs, have not disproved or proved claims of hospice care providers that they offer a more economical way of caring for the terminally ill because the hospice care patients and conventional care patients were not randomly assigned to the two forms of therapy. The question persists as to whether the selection process might be largely responsible for the cost differences noted.

Some of the findings have indicated that hospital-based hospice care patients who enter care from four to six months before death and who require a wide array of nursing services, homemaker services, social services, and counseling actually incur higher per-patient costs than patients receiving conventional care for the same time period.

The only published randomized comparison, by R. L. Kane et al, compares 137 patients in a hospice program with 110 patients outside the program.[8] The patients were under the care of the United States Vereran's Administration Wadsworth Medical Center, Los Angeles, California. The measurements of pain, symptoms, activities of daily life, or patient affect revealed no significant differences. However, hospice patients expressed higher satisfaction with their care, and their families were less anxious and more satisfied with the overall program as well. In these two groups hospice care did not reduce hospitalization, therapeutic procedures, or expenses of care. Interestingly, patient survival was essentially identical in both groups.

Because of the very few studies that are adequately designed to establish the significant advantages of hospice care programs, it is not possible to point to completely convincing evidence favoring or opposing their continued expansion. The evidence may be long in coming, in view of the many intangibles that are not measured at all or only with great difficulty in evaluations of hospice care. These difficulties have been set forth by D. S. Greer et al, in his analysis of the National Hospice Study currently in progress,[6] and B. C. Vladeck has editorialized against the practice of hospice evaluations based exclusively on cost-effectiveness arguments.[23] Questions have been raised about the capabilities of current methods to capture all the intangible, spiritual, and humanistic values embodied in the hospice movement. Yet the problem of evaluation remains in our society, faced with competing claims for increasingly scarce health care dollars.

Britain, with an experience three times as long as that in the United States, faces similar problems, an interesting fact in view of the National Health Service providing a contrasting system of administering and financing medical care. In a recent editorial in the British Medical Journal T. Smith itemized the following problems, all having a counterpart in the American scene:[19]

1. Payment for costly drugs in independent hospices.
2. Planning for distribution of hospices.
3. Training facilities for specialized physicians and nurses.
4. Division of responsibility for the dying between public and private programs.

5. If private, planning for distribution of hospices.

6. Setting and monitoring standards of performance.

7. Responsibility for training of specialized staff.

Smith continues: "What should not be allowed is a continuing drift with no planning, no long-term financial provision for running costs, and no system for either training or audit. Many people in the hospice movement are practical, experienced, and knowledgeable; what is needed is a meeting of the various charities and other parties with a view to achieving consensus."

This report, while it deals with the nature of hospice care in one state, will also deal with many of the issues facing hospice care providers throughout the nation. We hope that it will contribute to the development of a consensus in Massachusetts about the hospice movement. The recommendations are intended to strengthen the movement and direct it toward its major goals of compassion combined with excellence of care.

# CHAPTER TWO

## An Overview of Massachusetts Hospice Programs

### Variations in Hospice Care Programs

In Massachusetts the term "hospice care program" is used to describe a variety of organizations and agencies which are quite unlike each other. In size they range from large health care providers, with many employees to organizations with only one part-time paid staff member. The reasons for this variety of programs lie in the history of hospice care in Massachusetts. In the late 1970's, when hospice programs were initiated in Massachusetts, they were often based upon a core of volunteers, nurses, physicians, social workers and clergy, who provided "hands on service" free of charge to persons in their community who wished to die with dignity at home. Often these first programs operated with very little in the way of paid staff. As a result, costs were extremely low.

Some Massachusetts hospices have continued to provide "volunteer intensive services" to this day. However, as the demand for hospice care developed, many all-volunteer programs realized that they could not recruit enough volunteer professionals to serve all new patients. Therefore, hospice care administrators, in most cases, began to organize in-home care by obtaining the help of visiting nurse associations (VNAs) or hospitals, which were accustomed to providing care for seriously ill persons in their own homes.

Administratively these arrangements took two forms. Some hospice organizations maintained legal and financial independence while referring patients to VNAs or other agencies only when volunteers could not provide all needed services. Occasionally these referrals were made within the framework of a formal contract but often such referrals remained occasional and informal.

Other hospice organizations took the path of formal mergers with community-based VNAs or hospitals. Hospice programs, in most instances maintained a volunteer component, but by operating within another organizational framework, were freed of the administrative costs still being borne by volunteer-intensive hospices. The sponsoring organizations provided much of the day-to-day care required by the patients. The hospices themselves often have no budget of their own for this care.

A few Massachusetts hospices have developed a totally different type of organization which combines a group of volunteers with staff recruited, employed and paid by the hospice agency itself. However, this type of organization must be administered with extremely close attention to financial detail because there is no VNA, or hospital to provide financial support.

Recent Developments in Massachusetts

One of the most significant developments in Massachusetts has been the creation of the Hospice Federation of Massachusetts as an umbrella organization, bringing together all of these different types of hospice care programs. The Federation has given all hospice providers a way of making their particular needs and concerns known to legislators and regulatory groups.

In the Summer of 1984, a group composed of representatives of the Federation, the Massachusetts Hospital Association, Blue Cross of Massachusetts, the Massachusetts Association of Community Health Agencies and several Massachusetts state agencies served as members of a work group which was coordinated and staffed by the Office of Health Policy (OHP) of the Executive Office of Human Services. They published a report: Massachusetts Hospice Policy Update and Recommendations[11] which updated a previous policy statement published in 1980. Based on consultation with other interested parties and the results of a survey of providers, this report addresses three areas significant to hospice planning.

Reimbursement from Medicare -- The report reviews the controversy over the Health and Human Services (HHS) regulations which mandate direct service provision as opposed to contracting for needed professional services. The report advocates the recognition of "collaborative hospice programs" as eligible for reimbursement in addition to other models.

Plan for Inpatient Care -- The report discusses the controversy over the desire of the Hospice of the Good Shepherd to create its own inpatient unit for the provision of hospice care. In response, the Public Health Council approved a determination of need certificate for a demonstration project under a hospital license. The report surveyed other states to determine what their regulations were regarding hospice inpatient beds. It was found that no configuration was more prevalent than any other. Therefore, the policy statement recommends that three options be tested over a period of time: free-standing hospice care; inpatient units in hospitals devoted to hospice care; and scat-

tered beds in hospitals available to hospice care providers. The report also recommends that hospitals and hospice care providers develop a set of formal regulations for hospice care beds which will clarify how management of these beds differs from other hospital beds and to what extent they will be under control of the hospice.

Licensure -- the Office of Health Planning (OHP) supports the establishment of a state licensure program for all hospices. This could legitimize community-based programs, including those which do not wish to participate in the Medicare program. The report also recommends that the standards of the National Hospice Organization and the Joint Commision on the Accreditation of Hospitals be used as the basis of licensure.

In December of 1984 the recommendation relating to licensure was implemented by the passage of Massachusetts S.2056, An Act Authorizing the Department of Public Health to License Hospice Programs.[13/] This legislation states that the Department shall promulgate rules and regulations for licensure after a public hearing. However, the law lays down a number of guidelines for these regulations. Included among these are the following:

-- Hospice care must be provided or arranged to be provided through an interdisciplinary team, in a home setting, on an outpatient basis.

-- Hospice care programs must provide an inpatient back-up.

-- Hospice care services shall include (but are not to be limited to):

  - o physicians' services
  - o nursing care provided by or under the supervision of a regustered nurse
  - o social services
  - o volunteer services
  - o counseling services provided by professional or volunteer staff under professional supervision

-- The Department of Public Health shall provide financial assistance for the services of hospice programs licensed under this law.

The rules and regulations to be issued by the Department of Public Health will be extremely important since they will set the minimum requirements which Massachusetts hospices must meet. The legislation will probably cause a greater number of hospice programs to look at collaborative arrangements with other community-based programs. However,

the legislation encourages the continued development of community-based programs which contract for services rather than providing them directly.

The majority of Massachusetts hospice care programs already provide directly, or through contractual arrangements, all or most of the basic core services specified in this legislation. One problematical requirement will be for physicians' services to be available in the home. It has generally been the experience of hospices nationwide that arranging for home visits by doctors is difficult. In Massachusetts some hospices have successfully recruited physicians who volunteer to make home visits when needed. However, the Directory published by the Hospice Federation lists 13 (of 43) programs which provide all other basic services but are unable to guarantee physician visits.[7/]

## The Geographical Distribution of Hospice Care

Each of the 47 hospices listed in the Directory list its "catchment area" -- the communities it serves. In most parts of Massachusetts a city or town is served by only one hospice program. In a few instances two or three hospices list the same community as part of their catchment area. All of these occur in eastern Massachusetts where hospice care has the longest history. Agency mergers or agreements about catchment area boundaries are currently under negotiation in most of these cases. The map of hospice care programs which follows is based upon these catchment area descriptions.

The Directory also lists the services each program provides. This information was used to distinguish between those hospices providing the basic in-home services which will be required for licensure and those which do not. The 13 agencies which provide all in-home services except for physician visits were considered to provide "complete services" for the purposes of this report.

There are a few communities in Massachusetts not yet covered by an active hospice care program such as the southern and western portions of Worcester County.

# CHAPTER THREE

## Responses to UCPC Survey

### Methodology

In October, 1984 a United Community Planning Corporation survey form was mailed to 47 hospices listed in the Directory published by the Hospice Federation of Massachusetts. After three weeks each hospice which had not responded was contacted by UCPC staff. Another round of telephone calls reminding hospices of the survey was made in the first week of December. A second round of survey forms was mailed out to non-respondents in January, 1985.

The survey instrument included questions on the number of cases admitted to hospice care in 1983, the number provided home care only and the number hospitalized. It also included questions on the amount of funds expended for services and for administration as well as sources of income. Another group of questions related to existing referral systems, and the criteria for eligibility for service.

Through correspondence and telephone conversations it was determined that three hospices had merged with other programs since the Directory had been issued. One out-of-state hospice whose catchment area included only two small Massachusetts towns was not included in the survey. Thus, the number of hospices which might actually be expected to respond to our questionnaire was 43. Of these, 24 hospice programs (56%) provided usable information.

A Study Number was arbitrarily assigned to each program. Hospices will be identified by this number throughout the report.

### Survey Results

Table One displays some basic information about each hospice including the provision of Core Services required by the newly passed licensing bill. Cases accepted for service in 1983 will be referred to as the "caseload".

TABLE ONE

Caseloads and Core Services Provided
by Hospices Responding to Survey

| Study Number | Cases 1983 | Nursing | MD Visits | Social Services | Volunteer Services | Bereavement Counseling |
|---|---|---|---|---|---|---|
| 1 | 40 | x | x | x | x | x |
| 2 | 25 | x | x | x | x | x |
| 3 | 87 | x | x | x | x | x |
| 4 | NA | NA | NA | NA | x | x |
| 5 | 85 | x | x | x | x | x |
| 6 | 40 | NA | NA | NA | x | x |
| 7 | 32 | x | x | x | x | x |
| 8 | 142 | x | x | x | x | x |
| 9 | 58 | x | x | x | x | x |
| 10 | 84 | x | x | x | x | x |
| 11 | 102 | x | NA | x | x | x |
| 12 | 122 | x | x | x | x | x |
| 13 | 20 | NA | NA | NA | NA | x |
| 14 | 239 | x | x | x | x | x |
| 15 | 145 | x | x | x | x | x |
| 16 | 42 | x | NA | x | x | x |
| 17 | 60 | x | x | x | x | x |
| 18 | 46 | x | NA | x | x | x |
| 19 | 39 | x | NA | x | x | x |
| 20 | 23 | x | x | x | x | x |
| 21 | 136 | x | x | x | x | x |
| 22 | NA | x | x | x | x | x |
| 23 | 49 | x | x | x | x | x |
| 24 | 34 | x | x | x | x | x |
| | 1,650 | | | | | |

Key: X - service provided in home
NA - service not provided in home

The hospices which responded to the UCPC survey are for the most part those which provide all five of the basic services. Thus the hospices providing a smaller number of services are not proportionately represented. Some hospices which did not respond indicated that they faced shortages of administrative staff which precluded preparing answers to a lengthy survey instrument. Hospices did not respond to all items in the questionnaire. The following table compares the number of in-home services provided by all Massachusetts hospices with those provided by those which responded to our survey.

TABLE TWO

Number of Services Provided by Respondents

N=24

| | Total Number Mass. Hospices | Number of Survey Respondents | Responses as a Percentage of Total |
|---|---|---|---|
| Five Services Provided | 20 | 17 | 85% |
| Four Services Provided (In-Home MD visits excluded) | 13 | 4 | 24% |
| Three or Less Services Provided | 10 | 3 | 30% |
| TOTALS | 43 | 24 | 56% |

Table Two shows that 17 of the 20 hospices offering all five services responded to the UCPC questionnaire, four of the 13 hospices providing four services responded and three of the ten hospices providing three or fewer services responded. Interpretations of the data should be limited by the realization that the hospices which have responded were primarily those with larger staffs and, presumably, larger caseloads. We will now go on to discuss the survey results in detail.

# CHAPTER FOUR

## Unitization, Eligibility and Referral Networks

### Utilization

A study entitled Massachusetts Hospice Policy published by the Office of Health Policy of the Executive Office of Human Services summarized a survey of hospice care programs:[12/]

> "The total patient caseload reported by these programs was over 1,700 individuals in 1983. The two largest groups were 65 to 84 (56%), and 41 to 64 (30%). It was found that 97% of the patients were white, 55% were female and 96% had a primary caregiver at home. Ninety-five percent (95%) had a primary diagnosis of cancer, 2% of cardiac disease, 1% lung disease and less than 1% neuromuscular disease."

The same report investigated the extent to which cancer patients in Massachusetts were making use of hospice care programs. For these calculations, the Office for Health Policy developed some estimates based on 1982 cancer deaths and the number of persons admitted to hospices in 1983. These calculations were based on the simplifying assumption that all hospice care was used by cancer patients. It was found that statewide 16% of all terminal cancer patients availed themselves of hospice care. These statistics were aggregated by "Health Service Areas" which are used by the state Department of Public Health for planning purposes. These Health Service Areas do not correspond with the catchment areas of hospice care programs. Therefore, the calculations of Regional Utilization, while intrinsically interesting, are not unduplicated and hence are not accurate indicators of utilization of various hospice care programs.

In an effort to develop utilization figures for individual programs, we obtained through the cooperation of the Division of Health Statistics and Research of the Department of Public Health, a report on the number of persons who had died of cancer in 1983.[14/] The boundaries (where definable) of hospice program catchment areas were then used to aggregate the cancer death figures shown in the third column of Table Three. Case load figures from Table One, Column Two were used to calculate the proportion of potential patients who actually used the service.

TABLE THREE

Hospice Patients as a Proportion of all Cancer Deaths

-- Selected Geographic AReas -- 1983

N=18

| Study Number | Number of Hospice Patients | Total Number of Cancer Deaths in Catchment Area | Hospice Patients as a Percent of the total Number of Cancer Deaths |
|---|---|---|---|
| 2 | 25 | 236 | 11 |
| 5 | 85 | 202 | 42 |
| 6 | 40 | 222 | 18 |
| 7 | 32 | 143 | 23 |
| 8 | 142 | 232 | 61 |
| 10 | 84 | 358 | 24 |
| 11 | 102 | 253 | 40 |
| 12 | 122 | 306 | 49 |
| 13 | 20 | 63 | 32 |
| 14 | 239 | 503 | 48 |
| 15 | 145 | 440 | 33 |
| 16 | 42 | 246 | 17 |
| 17 | 60 | 178 | 34 |
| 18 | 40 | 665 | 7 |
| 20 | 23 | 189 | 12 |
| 21 | 136 | 484 | 28 |
| 23 | 49 | 164 | 30 |
| 24 | 34 | 93 | 37 |
| Totals | 1,420 | 4,968 | 29 |

Table three shows that the total of all patients (1,420) served by hospices is 29% of the total of all cancer deaths (4,968) in the selected catchment areas. This is almost twice as high as the 16% figure reported by the Office of Health Policy study. However, it should be remembered that the 18 hospices listed in Table Three include many of the largest in the state.

None of the hospices listed in Table Three cover any part of the City of Boston. There are four hospices serving various geographic areas in Boston. Of these, two did not respond to our survey and another responded but did not provide any caseload figures. The true availability of hospice care in the neighborhoods of Boston is unknown. Only additional studies based on larger number of hospice program responses can provide truly definitive information on Boston's utilization rates.

## Eligibility Criteria

There are five generally recognized eligibility criteria for admission to hospice in use by Massachusetts hospices today. The UCPC survey asked each program to identify its eligibility criteria. Twenty-three of the twenty-four responding programs provided usable responses which are summarized in Table Four:

TABLE FOUR

Criteria of Eligibility for Service Used by Hospice Care Programs

N=23

| Criterion | Number | Percentage of all Responding Hospices |
|---|---|---|
| Diagnosis of terminal illness with life expectancy of six months or less | 23 | 100% |
| Family and/or patient must accept the concept that only palliative care is to be provided | 15 | 65% |
| Patient must live in specific geographic area | 13 | 57% |
| Primary physician for patient must approve hospice care | 11 | 48% |
| Someone residing in the home to serve as primary caregiver to the patient | 10 | 43% |

Table Four indicates the unanimity of hospices in limiting hospice care to patients with a life expectancy of six months or less. In practice this policy limits hospice care almost exclusively to persons with a diagnosis of terminal cancer since their prognosis can be predicted with more accuracy than can the prognosis of persons with other terminal illnesses.

Table Four also shows that acceptance of palliative care by patient and family is required by 15 of the 23 hospice care programs. In some hospices, a signed document is necessary to cover the program legally in the event that a family later wishes to bring suit on the grounds of inadequate or inappropriate care. Others will not accept new patients until several conferences with family members have clarified all the ramifications of the decision to seek hospice care.

Table Five indicates how many hospices employ one or more of the criteria of eligibility. The relative number of referrals denied eligibility on the basis of each criterion is not covered in this survey. This might be taken up as part of a larger study of the accessibility of hospice care in Massachusetts.

TABLE FIVE

Number of Eligibility Criteria Employed by Hospice Respondents

N=23

| Number of Criteria | Number of Hospices Reporting | Percentage of Total Respondents | Cumulative Percentage |
|---|---|---|---|
| One | 3 | 13% | 13% |
| Two | 2 | 9% | 22% |
| Three | 11 | 48% | 70% |
| Four | 4 | 17% | 87% |
| Five | 3 | 13% | 100% |

The UCPC survey revealed that all respondent hospices require physician certification that death will occur in six months or less. We also heard anecdotal evidence from hospice care administrators that in some instances this criterion had proven difficult to operationalize. Physicians at best can only give a probable estimate of the patient's prospects, not an infallible prediction. For example, a doctor might say a patient has an 80 percent chance of death within six months.

A little less than half the hospices responding to our survey require a "personal caregiver" living in the home. Without further investigation it is impossible to determine how large an impact this criterion has on hospice use. Strict interpretation of this requirement would eliminate the possibility of providing hospice care to a sizable segment of the elderly population.

It should be pointed out, however, that there are hospice care programs in Massachusetts which pride themselves on their ability to serve patients who do not have family or friends available to play the role of personal care provider. By combining the services of homemakers, volunteers and VNA staff, a support system for such a patient can be organized

which will allow the patient to continue to live at home. An aggressive ingenuity is shown by these hospice care providers in mobilizing community-based services to assist such patients.

The requirement that families accept the concept that only palliative care is to be used may result in some refusal of hospice care. Hospice programs are well aware that hospitalization may be used in the interest of palliation or to provide respite for the patient's family.

Most families who seek hospice care wish to have the patient living at home in comfort and dignity until death comes. However some families are divided on this issue or some family members may have reservations about the acceptance of palliative care .

The Referral System

Preliminary interviews with Massachusetts hospice care providers indicated that each hospice program had developed its own sources of referrals and that these referral systems did not resemble one another. The UCPC survey asked each hospice care program to list its major sources of referral. Table Six displays the results.

TABLE SIX

Major Sources of Referral to Hospice Care Programs

N=24

| Source of Referral | Number* |
|---|---|
| Physicians | 15 |
| Staff of VNAs | 11 |
| Discharge planners of social service staff of hospitals | 10 |
| Families/Self/Other Patients | 10 |
| Hospitals -- not specified | 9 |
| Clergy | 2 |
| Community Social Agencies | 2 |
| Nursing Staff of Hospital | 1 |

* Respondents mentioned more than one referral source.

These results indicate a heavy reliance for referrals on physicians, the discharge planning staff of hospitals and VNA staff. Conversations with hospice care program directors during the process of gathering survey information indicated that many felt their programs had good support among the physicians of the community and some preferred that most of their referrals come from physicians. The sense of their comments seemed to be that since the patient's primary physician had to be in agreement with the use of hospice care anyway it was better that this physician refer patients directly. Furthermore, it is reasonable to assume physician-arranged referrals would favor physician involvement at critical moments in hospice care.

Massachusetts law requires each hospital to utilize discharge planners who may be social workers, public health nurses or both. It seems likely that the nine hospices which mention "hospitals" were referring to discharge planning staff.

Eligibility Determination

While referrals may come from many sources, each hospice care program develops its own method for processing requests for service. The survey asked each hospice who was responsible for the final decision regarding a patient's eligibility for hospice care.

Little agreement was found regarding the location of this responsibility. In nine instances, the medical director of the hospice program or the primary physician of the patient or both, working jointly with the program's administrator, made the decision. In seven cases, the hospice care team met regularly to discuss cases and to decide jointly on eligibility. In three hospices, the program's administrator made this decision alone. In the remaining five cases, responsibility was fixed with other officials such as the director of volunteer services or the director of nursing.

The hospices responding to our survey confirmed the comments of our earlier interviews with hospice directors that there was no single accepted referral system adopted by all hospice care programs. Provisionally, we can state that physicians seem to be more influential within the referral system than any other single group. In practice, it would be difficult for a patient to enter hospice care without the approval of his or her physician. Therefore, attitudes of local medical practitioners toward hospice care as an alternative way of treating the terminally ill are very important to hospice providers.

# CHAPTER FIVE

## Finances

### Programs

#### Not Reporting Medicare Payments

The UCPC survey of Massachusetts hospice programs requested detailed information about income and expenditures for 1983. Of the 24 programs which responded to the questionnaire only 11 (46%) provided enough information to permit analysis. Three of these programs reported receiving Medicare funds in 1983. However, none of these three hospices was certified by Medicare to participate in a hospice program. One was a Health Care Financing Administration demonstration site, one was a Blue Cross demonstration site, and one reported receiving Medicare payments which were actually paid to the VNA which sponsored the program. The other eight programs provided information which primarily related to their administrative costs and the funding they had obtained to support these costs.

The primary reason for the relatively low level of response to the financial section of our survey was that many hospice programs have no separate identifiable budget for the services provided to patients. Many hospice care program directors indicated, in telephone interviews, that they were administratively subordinate to the staff of their sponsoring agency such as a home health program (VNA) or a hospital. In such an administrative structure, services delivered to patients in the home are delivered by a combination of volunteers recruited by the hospice and staff employed and paid by the sponsoring agency. Payments to the agency for services to patients receiving hospice care are not distinguished from payments for homemaker, nursing or other services provided to patients not in the hospice program. This type of organization, in which hospice programs have no real financial identity of their own, is probably the most widespread administrative arrangement in Massachusetts.

### Expenditures

Table Seven displays the 1983 expenditure information from hospices not reporting Medicare payments. Table Ten displays the expenditures of the three hospices which reported receipt of Medicare payments for 1983.

TABLE SEVEN

Expenditures of Hospice Programs not Reporting Medicare Payments -- 1983

N=8

| Study Number | Number of Cases In 1983 | Services* | Administrative | Total Budget | Total Expenditures Per Case |
|---|---|---|---|---|---|
| 6 | 40 | $ 2,000 | $ 10,199 | $ 12,199 | $ 304.97 |
| 7 | 32 | 7,200 | 23,800 | 31,000 | 968.75 |
| 9 | 58 | 1,728 | 48,870 | 50,598 | 872.37 |
| 10 | 84 | 7,000 | 0** | 7,000 | 83.33 |
| 12 | 122 | 9,574 | 48,164 | 57,738 | 473.26 |
| 13 | 20 | 1,196 | 20,696 | 21,872 | 1,093.60 |
| 20 | 23 | 0 | 41,000 | 41,000 | 1,782.60 |
| 23 | 49 | 22,629 | 22,000 | 44,629 | 910.79 |

* "Services" include nursing, social services, training and supervision of volunteers, and other supportive activities.

** All administrative work of this hospice is done by volunteers.

Variations among the eight respondents in Table Seven which include the following:

-- Range of 1983 case load from 20 to 122 clients.

-- Range of cost of services from $ 0 to $22,629.

-- Range of administrative costs from $ 0 to $48,870.

-- Range of budget size from $7,000 to $57,738.

-- Range in total cost per case from $83.33 to $1,782.60

It must be emphasized that the amounts listed in the "Services" column represents a very small proportion of the amounts actually expended by other health providers to pay visiting nurses, homemakers, physicians, social workers and others for the care of the terminally ill patients. However, the organization and financial arrangements of these hospices not reporting Medicare payments are such that their budgets are

largely composed of administrative costs. Hospice #23 is an exception to this since it made a search of its records to reveal true service costs.

It should also be noted that these figures do not include the expenditures for inpatient care in hospitals which may have been incurred in 1983. Records documenting these costs are not generally kept by the hospice. The following table displays what little information was submitted regarding inpatient care of hospice patients.

TABLE EIGHT

Number of Patients Hospitalized During Hospice Care --

Hospices Not Reporting Medicare Payments

N=4

| Study Number | Case Load | Patients Hospitalized | Total Number of Patient Days | Average Length of Stay |
|---|---|---|---|---|
| 6 | 40 | 14 (35%) | 112 days | 8 days |
| 7 | 32 | 29 (91%) | 319 days | 11 days |
| 13 | 20 | 5 (25%) | NA | 7 days |
| 20 | 23 | 9 (39%) | 197 days | 18 days |

Table Eight shows that hospices varied greatly in the extent to which they utilized hospitals. None of these hospices were associated with a hospital; hence, it is not possible to confirm or not confirm findings of the National Hospice Study that hospital-based hospices made more use of inpatient care.

Because no information was made available regarding the total cost of inpatient care, it is not possible to indicate the extent to which hospice care expenditures would be escalated by including them. It appears likely that the increases would prove substantial, however, since it is reasonable to assume average daily charges of more than $500.

Income

The UCPC survey requested hospice programs to provide specific information on the sources of their funding. Eight hospices provided usable responses. These are listed in Table Nine below.

TABLE NINE

Sources of Revenue of Hospice Programs Not Reporting Medicare Payments

N=8

| Study Number | United Way Allocation | Contributions | Fund-raising | Grants | Other | Total |
|---|---|---|---|---|---|---|
| 6 | $ 5,000 | $ 5,123 | $ 3,032 | $ 1,000 | $ 927 | $ 15,082 |
| 7 | 0 | 1,666* | 0 | 10,500 | 20,500 | 32,666 |
| 9 | 4,200 | 17,066 | 14,179 | 8,500 | 2,251 | 46,196 |
| 10 | 26,500 | 10,000 | 3,000 | 3,000 | 0 | 42,500 |
| 12 | 0 | 7,605 | 28,524 | 16,160 | 1,884 | 54,173 |
| 13 | 0 | 11,050 | 9,342 | 3,875 | 0 | 24,267 |
| 20 | 0 | 4,000 | 0 | 0 | 0 | 4,000 |
| 23 | 0 | 0 | 4,122 | 12,000 | 22,609 | 38,731 |
| Totals | $ 35,700 | $ 56,510 | $ 62,199 | $ 55,035 | $ 48,171 | $257,615 |

* Estimated proceeds from a three-year pledge

Table Nine shows that just over half of the income of hospices not reporting Medicare payments came from fund-raising or contributions. Comments made by some respondents indicated that contributions were most often in memory of a patient who had benefited from hospice care.

As with many other aspects of hospice care, fund-raising is largely the responsibility of volunteers. Many of these programs have become the focus of fund-raising efforts by social clubs, recreational groups and schools. It is this type of vigorous grass roots involvement which has kept hospices viable in various parts of the state.

## Participation in Medicare

When the United States Congress established hospice care as a benefit under the Medicare program, there was a general expectation among policy makers in Washington that hospice programs throughout the country would enthusiastically seek to participate. However, the subsequent issuance

of restrictive regulations by the Department of Health and Human Services resulted in a storm of criticism from hospice care providers and a general slowing in applications for participation.10/

In Massachusetts there was a particular concern regarding the requirement, made explicit in the regulations, that each hospice be "free-standing." This means that hospices, if they wish to participate in Medicare, must be legally and financially independent from sponsoring organizations such as VNAs or community hospitals.

In addition to this requirement the Medicare regulations issued by the Department of Health and Human Services contained several other requirements which caused deep concern among hospice care providers in Massachusetts as well as many other states. For example, the regulations specify that a patient cannot elect hospice benefits unless he "has a medical prognosis that life expectancy is six months or less." If a person survives for 210 days (seven months) he will have used up his benefits and will be ineligible for further coverage. However, Federal law is emphatic in stating that hospices must and will provide undiminished care of all patients after the 210-day period.

To qualify for Medicare participation a hospice must directly provide four "core services": nursing care, social services, physician's services and counseling. The term "direct" is defined as requiring that the persons delivering this service be employed by the hospice program. These persons may be volunteers or paid staff. Since many hospice programs contract with or refer to other community-based programs to provide these types of care, this regulation will require adding many staff persons to the hospice payroll as a condition of certification by the Medicare program.

The Medicare regulations established the following daily rates (adjusted for the Greater Boston area): routine home care $56.64, continuous home care $382.06 (for 24-hours of care), general inpatient care $287.46, inpatient respite care $58.17. Total reimbursement for any hospice for a year cannot exceed a figure of $6,500 multiplied by the total number of patients in hospice care. Some Massachusetts hospice providers indicated that the "cap" had the practical effect of rewarding those hospices which accept many patients who have only a few weeks to live.

The three hospices which reported receiving Medicare funds in 1983 served a total of 466 cases which was 28% of all the patients served by our sample. All three are located in Greater Boston. Two were developed by home health care organizations while the third has been free-standing since its inception.

The following table displays the total expenditures reported by these three hospices.

TABLE TEN

Expenditures of Hospice Programs Reporting

Medicare Payments -- 1983

| Study Number | Caseload | Nursing | Home-maker | Other Services | Drugs and Equip-ment | Admin-istra-tion | Total | Cost p Case |
|---|---|---|---|---|---|---|---|---|
| 5 | 85 | $ 61,157 | $140,071 | $81,962 | $ 0 | $94,357 | $304,547 | $ 3,5 |
| 8 | 142 | 190,719 | 110,100 | 54,736 | 47,193 | 18,736* | 421,484 | 2,9 |
| 14 | 239 | 123,544 | 71,732 | 34,761 | 41,445 | 133,231 | 404,713 | 1,6 |

* Additional administrative costs spread proportionately over "Other service

The column headed "Other Services" includes occupational, physical and speech therapy, physician visits, visits by social workers and clergy as well as volunteer training and supervision.

"Administrative Costs" include the salaries of administrators, office rental, telephones, equipment and travel.

It should be noted that these expenditures are for care in the homes of patients only. The UCPC survey requested each hospice to provide information about hospice care clients admitted to hospitals for in-patient care during their hospice service. The following table displays this information from those three hospices which reported Medicare payments.

TABLE ELEVEN

Number of Patients Hospitalized During Hospice Care Programs Reporting Medicare Payments -- 1983

N=3

| Study Number | Case Load | Patients Hospitalized | Total Number of Patient Days | Average Length of Stay |
|---|---|---|---|---|
| 5 | 85 | 36 (42%) | 670 | 19 days |
| 8 | 142 | 107 (75%) | 994 | 7 days |
| 14 | 239 | 70 (29%) | 840 | 12 days |

Table Eleven shows a pattern of a wide variation in utilization of hospital beds. Three-quarters of the patients admitted to Hospice #8 were hospitalized but stayed for a shorter average length of time. The other two programs hospitalized fewer than half of their patients, but the average length of stay was longer (the range was 29% to 75%).

Information was not provided about average cost-per-patient day or total hospital costs. However, it would appear that if these costs were charged to the hospice care programs they would represent a substantial increase in the total program costs since average daily hospital costs could exceed $500. Some hospice providers have recently developed new written agreements with local hospitals which set much lower daily rates for brief hospital stays.

Information provided by respondent hospices indicated that admission to an inpatient facility was usually required for pain control, symptom management and/or respite care for the family of the patient.

The three hospices reporting Medicare payments provided much more detailed information about their funding than did the eight hospices not receiving Medicare funds. Table Twelve displays these income figures.

TABLE TWELVE

Sources of Revenue of Hospice Programs Reporting Medicare Payments - 1983

N=3

| Source | Hospice #5 | Hospice #8 | Hospice #14 | Total |
|---|---|---|---|---|
| Medicare | $ 50,677 | $ 351,063* | $ 172,263 | $ 574,003 |
| Medicaid | 53,438 | 0 | 15,205 | 68,643 |
| Blue Cross | 62,932 | 59,439 | 77,109 | 199,480 |
| Private Insurance | 0 | 105,248 | 21,560 | 126,808 |
| Private Pay | 1,449 | 0 | 945 | 2,394 |
| United Way | 0 | 0 | 4,500 | 4,500 |
| Contributions | 2,500 | 144,253** | 30,000 | 179,147 |
| Fundraising | 0 | 0 | 13,000 | 13,000 |
| Grants | 7,361 | 10,000 | 965 | 18,236 |
| Other | 21,672 | 15,176 | 16,000 | 63,848 |
| Total | $ 211,329 | $ 685,179 | $ 351,547 | $1,248,055 |

* Hospice #8 received HCFA demonstration grant funds in 1983.

** Hospice #8 included capital fund-raising proceeds with contributions.

Table Twelve shows that Hospices #5 and #14 were heavily dependent upon a combination of Blue Cross, Medicare and Medicaid funding in 1983. Hospice #8, on the other hand, had conducted a special drive for capital contributions in that year and also benefitted from a special HCFA grant in the same year. Because such a small number of hospices are included in this sub-sample, it is impossible to predict how funding patterns will develop in future years.

Deficits and Surpluses Among the Hospices -- A Summary

The UCPC survey of Massachusetts hospices requested each respondent to estimate its overall surplus or deficit for calendar year 1983. Because of differences in bookkeeping practices it proved impossible to simply derive these figures from the expenditures and revenues presented.

All eight not receiving Medicare payments replied to this section of the questionnaire:

-- Hospice #6 reported a surplus of $2,882. This agency indicated that services were volunteered by physicians, nurses and non-professionals which would allow it to continue to operate at or near a break-even point.

-- Hospice #7 reported that it "broke even" in 1983. This agency expected to reduce "secretarial and managerial" hours in order to maintain or increase the hours of nursing care it provided.

-- Hospice #9 reported it did not know if it was operating at a surplus or a deficit.

-- Hospice #10 reported it "broke even" in 1983.

-- Hospice #12 reported that it operated at a deficit of $3,562 in 1983 and that it planned to raise additional funds in the private sector to meet this deficit.

-- Hospice #13 operated with a surplus of $2,500 but made no further comments regarding its finances.

-- Hospice #20 stated that it "broke even" in 1983. This hospice stated that it paid $1,000 for bereavement counseling and $6,000 for the services of the medical director which could not be recovered from reimbursement programs. However, this agency also stated that it was sponsored by a VNA which "absorbed all administrative costs."

-- Hospice #23 reported that it operated at a deficit but did not state exactly how great it was. This hospice stated that it would probably merge with another hospice or "discontinue the program completely."

With the exception of hospice #23, these eight programs appear, for the most part, to be in good fiscal health. We emphasize that this is a small sample of the total hospice effort. Record-keeping is not uniform throughout the hospice movement and evidently is not always designed to document all hospice care costs. For example, volunteer activities are not given an estimated dollar value. Because some hospices make use of a substantial amount of volunteer time, they are able to operate at a small deficit or even with a surplus.

It should be reiterated, however, that these financial statements do not reflect the problems currently being faced by other community-based health care providers, especially VNAs, whose costs and revenues are not

included in the budgets of hospice care programs. These agencies are providing hospice services to patients admitted to hospice care programs while billing Medicare, Medicaid and other third-party payers at the unit rates for their regular home health services. This is an arrangement which evolved in the early days of hospice care. In the long run, however, since hospice services are more costly than other home care services, this will prove disasterous since the unit rates are not commensurate with costs, including costs of hospital stays.

The fiscal pictures of the three hospices reporting Medicare payments in 1983 differed markedly from one another. Two operated at deficits each totalling more than $50,000. Only Hospice #8 operated at a surplus. Regarding their surplus/deficit position their specific responses were:

-- Hospice #5 estimated its overall deficit at $51,636. Included in this was a total of $8,000 for bereavement counseling. This hospice did not know how this deficit was to be dealt with.

-- Hospice #8 operated at a surplus of approximately $200,000 although the exact amount could not be determined. This surplus was primarily the result of a one-time HCFA demonstration grant in 1983 as well as capital funds included among "contributions". This hopsice indicated it had expended $5,450 for bereavement counseling and $10,000 for an arts program which could not be reimbursed under existing programs. This hospice also indicated that all surplus monies offset the costs of meeting free or reduced fee care to those who needed it.

-- Hospice #14 operated at a deficit of $53,167 in 1983 which included $20,000 in pastoral counseling, $9,000 in bereavement counseling, $8,000 in volunteer support, and $5,000 for social work services which could not be reimbursed. This hospice indicated that an increase in memorial contributions and a fund-raising event has erased this deficit.

The three hospice programs anticipate losses insofar as the prospective rates of Medicare payments do not meet the full costs of operation. However, it still seems too early to estimate the extent of such losses.

Hospices which participate in the Medicare program will have to maintain fairly high case loads in order to achieve economies of scale. They will have to be continuously alert to see that their reimbursements do not drop too far behind the costs of service. In all likelihood they will not be able to rely entirely upon Medicare but rather may need to fund-raise vigorously in their local communities to meet the costs of bereavement counseling and other non-reimbursed services.

On the other hand, the smaller, "grass roots" hospices will also be forced to raise funds each year in order to meet their administrative and volunteer-related costs. With no stream of public funding to draw upon, they may find such yearly fund-raising more and more problematical given the many other services and programs which are also seeking private charitable contributions.

## CHAPTER SIX
## RECOMMENDATIONS

The first chapter of this report cited a recent editorial in a British medical journal which criticized the hospice movement in that country for its "continuing drift."[19] The writer called for better planning for the distribution of hospices, more adequate financial support for operating costs and systematic programs of training and evaluation of performance.

The findings of the UCPC survey of Massachusetts hospice care providers suggest that many of the same issues may be found on the local scene. Basic to an understanding of hospice care in the Commonwealth is the realization that a tremendous amount of unplanned growth has taken place in a very short time. A substantial number of health professionals and other citizens have been attracted to the idea of a dignified and humane alternative to traditional hospital care for terminally ill patients.

Many different models of hospice care have been created in Massachusetts. Providers interviewed for this study have pointed out that they have enjoyed the freedom to seek ways of serving their particular communities rather than being hemmed in by centralized planning. Lack of planning, however, has resulted in overlapping catchment areas in some parts of Essex, Middlesex, and Norfolk counties and the absence of services in some other areas.

The passage of legislation requiring the Department of Public Health to license hospice care programs indicates that a more planned approach to growth is seen to be necessary. The recommendations of this report have the general thrust of assisting and facilitating this movement toward a more controlled growth of hospice care as well as providing patients with improved access to the service.

### Recommendation One

That the Hospice Federation of Massachusetts, in cooperation with the Department of Public Health and other interested parties should organize and convene a small group of hospice care professionals, regulators and funders to discuss the current state of planning in this field. This report, which describes part of the hospice care system, could be used along with the findings of other studies as the basis for a continuing series of discussions.

Recommendation Two

That Massachusetts hospices begin to share basic data regarding their service patterns, financing patterns and management practices. A single registry of patients should be established to provide a data base for future planning. Efforts to implement this recommendation might be undertaken by the Hospice Federation of Massachusetts, the Massachusetts Department of Public Health, the Massachusetts Health Data Consortium, the Cancer Registry and other groups.

Recommendation Three

That a detailed and accurate survey of the current geographical distribution of hospice care program catchment areas be prepared. Merger discussions are now ongoing between some of the geographically contiguous hospice programs. A fresh look at geographical coverage on a state-wide basis would assist these discussions.

Recommendation Four

That organizations concerned with the availability of health care for low-income persons should study the utilization of hospice care by various socio-economic groups especially racial and ethnic minorities.

Recommendation Five

That hospice care providers begin to study more closely the cumulative effects of the various eligibility criteria currently in use. This activity could best be pursued after the establishment of the shared data base mentioned in Recommendation Two.

Recommendation Six

That the various sources of financial support for hospice care programs monitor the financial effects of current Medicare regulations, the levels of reimbursement set by the state Rate Setting Commission and the licensing process now underway. The need for extra resources to meet some of the licensing standards should be watched closely. The funds for hospice care should be disbursed in accordance with an overall plan for the orderly and equitable development of the service.

REFERENCES

1/ Adams, A. B., Dilemmas of Hospice, a Critical Look at its Problems. CA 1984; 34:183-90.

2/ Aiken, L. H. and Marx, M. M., Hospices: Perspectives on the Public Policy Debate. Am. Psychol. 1982; 37:1271-79.

3/ Bayer, R., Callahan, D. Fletcher, J., et al. The Care of the Terminally Ill: Morality and Economics. New England Journal of Medicine. 1983; 309:1490-1494.

4/ Birnbaum, H. G., and Kidder D. "What Does Hospice Cost?" American Journal of Public Health, 74, 689-697, 1984.

5/ Brown University. Preliminary Report of the National Hospice Study. Providence, 1983.

6/ Greer, D. S., Mor, V., Sherwood, S., Morris, J. N., and Birnbaum, H. "National Hospice Study Analysis Plan." Journal of Chronic Diseases. 36, 737-780, 1983.

7/ Hospice Federation of Massachusetts, Inc. Hospice Directory for Massachusetts. Wayland, 1983.

8/ Kane, R. L., Wales, J., Bernstein, L., Leibowitz, A., and Kaplan, S.A., "Randomized Controlled Trail of Hospice Care." Lancet 890-894, 1984.

9/ Kleckner, H. B., Vinciguerra, V. and Degnan, T. J. "Letters to the Editor." New England Journal of Medicine. 312, 440-441, 1985.

10/ McLaughlin, S. "Final Hospice Regulations Published." Caring, 5-8 Feb. 1984.

11/ Massachusetts Executive Office of Human Services. Massachusetts Hospice Policy, Update and Recommendations, Boston, 1984.

12/ Massachusetts Executive Office of Human Services. Summary of 1983 Hospice Survey Results, Boston, 1983.

13/ Massachusetts Legislature. Senate. An Act Authorizing the Department of Public Health to License Hospice Programs (Sen 2056), Boston, 1984.

14/ Massachusetts Department of Public Health, Division of Health Statistics and Research, Selected Causes of Death by City and Town of Residence, 1983. Unpublished data.

15/ Mount, B. M. and Scott, J. F., "Whither Hospice Evaluation." Journal of Chronic Diseases. 36, 731-736, 1983.

16/ Rainey, L. C., Crane, L. A., Breslow, D. M., and Ganz, P. A., "Cancer Patients' Attitudes Toward Hospice Services." CA 34, 191-201, 1984.

17/ Rees, W. D., "Role of the Hospice in the Care of the Dying." British Medical Journal, 285, 1766-1768, 1982.

18/ "Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death." Journal of the American Medical Association. 205, 337-340, 1968.

19/ Smith, T., "Problems of Hospices." British Medical Journal, 288, 178-179, 1984.

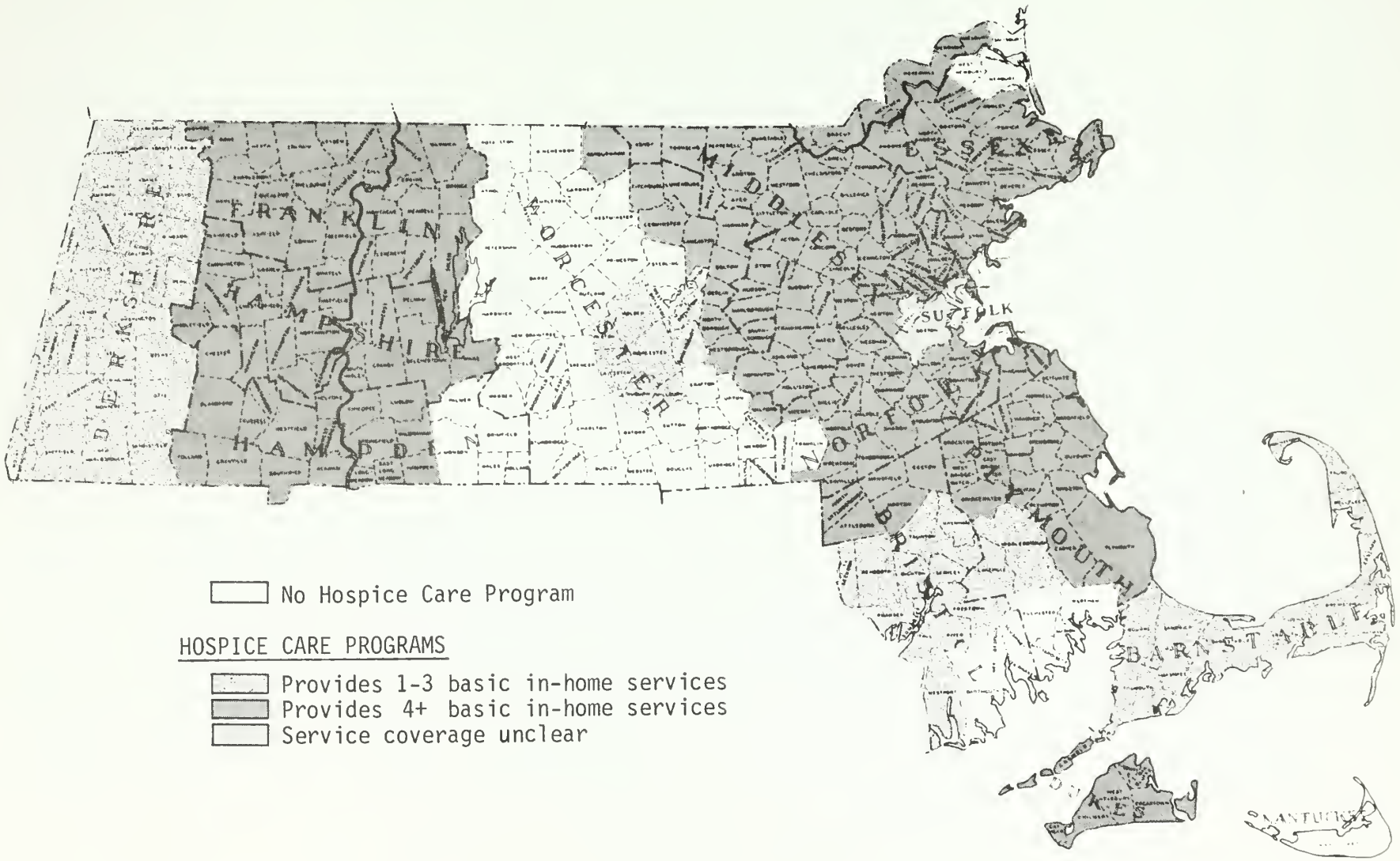
20/ United Community Planning Corporation, The Health Concerns Committee. Hospice: A Status Report on Care for the Terminally Ill, Boston, 1981.

21/ United States Bureau of the Census, Statistical Abstract of the United States 1982-83 (103d ed) Tables 30 and 62, Washington, 1982.

22/ Vanderbos, G. R., DeLeon, P. H., and Pallak, M. S. "An Alternative to Traditional Medical Care for the Terminally Ill," American Psychologist, 37, pp. 1245-1248, 1982.

23/ Vladeck, B. C., "The Limits of Cost-Effectiveness," American Journal of Public Health, 74, pp. 652-653, 1984.

# MASSACHUSETTS HOSPICE CARE SERVICES -- EXTENT OF COVERAGE



APPENDIX TWO

WHAT IS HOSPICE?

(From A Consumer Guide to Hospice Care, National Consumers League, Washington, D.C.)

Although hospice organizations vary widely, they all generally agree that a basic program of hospice care should include:

- Helping with the physical, emotional, social and spiritual needs of a dying person and the person's family.
- Placing control of care in the patient's hands and encouraging patient and family to work together with the hospice staff.
- Providing support and assistance from a hospice team of physicians, nurses, social workers, trained volunteers and chaplain.
- Being on call 24 hours a day, 7 days a week.
- Managing the patient's pain and other troubling symptoms so that he or she can be as comfortable and alert as possible.
- Creating as pleasant an environment as possible for the patient if he or she is not at home - a setting which allows for frequent presence of family and friends.

Differences between Hospice and Conventional Care

Hospice is called "palliative" care, which means that the care is intended to ease pain without curing. It also means that no attempt is made to prolong life beyond its natural end. On the other hand, hospice does nothing to hasten death.

Hospice programs do not generally include surgery, routine intravenous therapy or blood transfusions, nor place people on respirators, unless one of these procedures could relieve pain and make the patient more comfortable.

The difference with a hospital is that a person is allowed to die when the time comes, not kept alive by machines or resuscitated.

Hospice also differs from hospitals in working with the whole family, not just the patient, and in allowing the patient and family to make the major decisions about a program of care. Support continues to be offered to the family even after the death of the patient.

By giving control to the patient, hospice tries to help the dying maintain their dignity and their individuality which can be easily lost in a hospital setting where the hospital personnel decide the schedule and events of a patient's life.

Also, hospice uses a team approach to the care of patients - a team made up of trained medical and counseling professionals and volunteers. The family is considered part of the team.

Lastly, in a hospice program, drugs and medication are administered by the patients themselves or their families under the guidance of a physician. Hospice also believes that drugs or medicine should be allowed in sufficient dosages to prevent pain from developing or to reduce it to the lowest possible level, while still allowing the patient to be mentally alert.

Although the differences between conventional treatment in a hospital and hospice are clear, it is more difficult for people sometimes to understand the distinction between home care in general and hospice home care.

Many home care agencies, hospitals and other organizations offer home care programs for the terminally ill. These programs provide nurses, therapists and home health aides to help with patient care in the home. These programs do not usually attempt, however, to provide the comprehensive services of a hospice nor are services generally provided for the whole family.

APPENDIX THREE

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